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ABSTRACT

This progress report reviews federal policy activities toward the inclusion, empowerment, and independence of people with disabilities consistent with the vision of the Americans with Disabilities Act of 1990 (ADA). The report covers the period of November 1, 1997, through October 31, 1998. It notes progress where it has occurred and makes further recommendations in the following areas: (1) disability research; (2) civil rights; (3) education; (4) health care; (5) long-term services and supports; (6) immigrants, and racial and ethnic minorities with disabilities; (7) Social Security work incentives and Social Security solvency; (8) employment; (9) welfare to work efforts; (10) housing; (11) transportation; (12) technology; and (13) international issues. The review indicates that the rate of progress is slower and less steady than many in the disability community had hoped when ADA was enacted into law, and that federal policy remains rife with inconsistent messages and unrealistic requirements for people with disabilities who rely on federal programs like Social Security disability benefits, vocational rehabilitation, Medicaid, Medicare, special education, and Temporary Assistance for Needy Families. In addition, it warns that the backlash against civil rights for children and adults with disabilities continues to motivate attempts to weaken disability laws. (CR)

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National Disability Policy: A Progress Report, November 1, 1997–October 31, 1998

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

February 16, 1999

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit NCD's *National Disability Policy: A Progress Report*, as required by Section 401(b)(1) of the Rehabilitation Act of 1973, as amended. This report follows up on last year's progress report and on NCD's 1996 report and recommendations capturing the input of disability community leaders throughout the country at a summit held in 1996. That report, *Achieving Independence*, included more than 120 recommendations for change in a wide range of areas of public policy designed to facilitate inclusion, empowerment and independence of people with disabilities consistent with the vision of the Americans with Disabilities Act of 1990 (ADA). These recommendations were elaborated upon in the 1997 progress report.

The attached progress report, which covers the period November 1, 1997, through October 31, 1998, reviews federal policy activities in the year following our last report, noting progress where it has occurred and making further recommendations where necessary. The recommendations apply to the executive branch, to the legislative branch, and in some instances to both. Overall, NCD believes the country continues to move forward in expanding opportunities and inclusion for Americans with disabilities.

Nonetheless, the rate of progress is slower and less steady than many in the disability community had hoped when ADA was enacted into law. Federal policy remains rife with inconsistent messages and unrealistic requirements for people with disabilities who rely on federal programs like Social Security disability benefits, vocational rehabilitation, Medicaid, Medicare, special education, and Temporary Assistance for Needy Families. In addition, the backlash against civil rights for children and adults with disabilities continues to motivate attempts to weaken laws like the Individuals with Disabilities Education Act and ADA.

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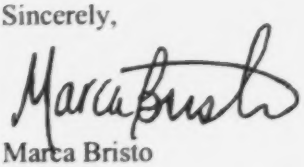
For people with disabilities truly to accomplish the vision of ADA, it is critical that the Administration work with leaders in Congress to forge a disability agenda that brings children and adults with disabilities into the mainstream of American life.

Thank you for the opportunity to play the independent role that our mission requires and to offer an objective assessment of progress in the last 12 months. NCD stands ready to work with you and stakeholders outside the government to see that the public policy agenda set out in the attached report, in *Achieving Independence*, and in other NCD reports is implemented.

Sincerely,



Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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TABLE OF CONTENTS

Preface vii

Introduction 1

Progress, Concerns, and Recommendations 7

A. Disability Demographics and Disability Research 7

1. Demographics 7

2. Research Challenges 9

B. Civil Rights 10

1. U.S. Supreme Court Speaks on ADA 11

2. Hate Crimes 12

3. Civil Rights Enforcement 12

4. Civil Rights Backlash 14

5. Access to the Electoral Process 15

6. Wilderness Accessibility 16

C. Education 17

1. Omnibus Fiscal Year 1999 Budget Bill 17

2. School Modernization 18

3. IDEA Proposals 18

4. Charter Public Schools 22

5. Elementary and Secondary Education Act 23

6. Education of the Deaf Amendments of 1998 23

D. Health Care 24

1. Protections in Managed Care 24

2. Medicare Reform 25

3. Medicaid Buy-in 25

4. Assisted Suicide 26

E. Long-Term Services and Supports for Individuals and Families 27

1. Federal Legislative Efforts 27

2. Administration Efforts 28

3. Family Support 29

4. Child Care 30

F. Immigrants, Racial, and Ethnic Minorities with Disabilities 30
1. President's Initiative on Race 31
2. Health-Related Funding in Minority Communities 32
G. Social Security Work Incentives and Social Security Solvency 33
1. Work Incentives 33
2. Social Security Solvency 35
H. Employment 36
1. Job Training and Vocational Rehabilitation 36
2. Presidential Task Force on Employment of Adults with Disabilities 38
I. Welfare to Work 39
1. Federal/State Efforts 39
2. Increased Federal Funding 40
J. Housing 40
1. Definition of Housing for People with Disabilities 41
2. Home Purchase and Renovations 41
3. Visitability 42
4. Tenant-Based Rental Assistance 42
5. Task Force on Segregation and Services Linked to Housing 43
6. Compliance with Section 504 of the Rehabilitation Act by HUD and its Grantees 43
K. Transportation 44
1. Over-the-Road Bus Regulations 44
2. Air Carrier Access Act 46
L. Technology 47
1. Section 508 of the Rehabilitation Act 47
2. Section 255 of the Telecommunications Act 48
3. ADA and Section 504 of the Rehabilitation Act 49
4. Assistive Technology Act 49
M. International Issues 50
1. Organization of American States 50
2. Department of State 50

Conclusion 53

Appendix

Mission of the National Council on Disability 55

PREFACE

The National Council on Disability (NCD) is an independent federal agency charged with advising the President and Congress on public policy issues affecting people with disabilities. Consistent with this mission, NCD is required to report annually on the progress made in federal policy for people with disabilities and to make recommendations for how public policy might better meet the needs of the disability community. Given the diverse nature and large size of the disability community and the range of public policy issues affecting this community, NCD has tried to focus on issues that could affect large segments of the disability community in the United States.

As indicated on the title page, the following report covers the period from November 1, 1997, through October 31, 1998. NCD assesses developments in multiple areas of public policy against the yardstick of NCD's previous reports and recommendations. The principal report that forms the framework for NCD's policy analysis is its 1996 report, *Achieving Independence*, which captured the consensus recommendations of a diverse group of over 300 disability leaders from around the country who gathered in a summit in Dallas that year.

To assist the reader, the following report below uses italics for text that includes NCD's recommendations for the President and/or the 106th Congress.

INTRODUCTION

On July 26, 1990, when he signed the Americans with Disabilities Act (ADA) into law, President George Bush said:

> *ADA is powerful in its simplicity. It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard. Independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the right mosaic of the American mainstream.*

President Bush later stated, "When you add together federal, state, local and private funds, it costs almost $200 billion annually to support Americans with disabilities, in effect, to keep them dependent." As President Bush recognized, the dependence-oriented model of our systems of public income supports and corresponding health care benefits is not consistent with ADA's vision of freedom of choice and equal employment opportunity. If you must lose your health care and personal assistance services when you take a job, is that equal employment opportunity?

In an effort to address in our public disability benefit programs the ongoing barriers to work, members of Congress engaged in a bipartisan, bicameral strategy this past year to allow people with disabilities to leave the disability benefit rolls and maintain their health coverage when they take a job. Another important component of the strategy would have expanded access to private vocational rehabilitation for people on the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) rolls. The return-to-work bills captured the attention of people with disabilities, their families, and advocates across the country as news of them arrived by e-mail, facsimile, telephone, and letter. Through the hard work of disability advocates and the bills' chief sponsors, the Ticket to Work and Economic Self Sufficiency Act in the House and the Work Incentives Improvements Act in the Senate gained the support of the Administration and almost became law. The progress made on this issue in the 105th Congress will form a solid foundation on which to build a successful bipartisan effort in the 106th Congress.

Independent of the return-to-work effort, reform of the Social Security and Medicare programs will be high on the list for both parties in the 106th Congress. As with other high

policy priorities such as school modernization, managed care reform, physician-assisted suicide, or the implications of the human genome project, the manner in which Social Security solvency and the future of Medicare are resolved will have a great impact on people with disabilities. And yet, despite this, too few working-age people with disabilities and their advocates have participated in the ongoing discussions about how to protect the solvency of the Social Security Trust Fund or the future of the Medicare program. As more people with disabilities, their families and advocates speak out on Social Security and Medicare issues, the challenge they face will be defending the existence of basic federal income support programs and publicly funded health care coverage for those unable to work, while at the same time pushing for expanded access to affordable health and long-term services and supports for people with disabilities who seek employment. This challenge is present in many areas of public policy today. Should people with disabilities fight to protect important but poorly designed and poorly managed public programs as these programs come under heightened scrutiny, or should they proactively work to modernize public programs so that work and economic self-sufficiency will truly be promoted?

President Clinton recognized the need to modernize and coordinate federal policy to promote employment of people with disabilities on March 13, 1998, when he signed an executive order establishing a National Task Force on Employment of Adults with Disabilities. He named Labor Secretary Alexis Herman as chair and Tony Coelho of the President's Committee on Employment of People with Disabilities as vice chair. In the National Council on Disability's (NCD's) 1996 report *Achieving Independence*, which summarized the recommendations from a summit attended by a diverse group of over 300 disability community leaders from around the country, NCD recommended that the President sign an executive order directing the secretary of labor to promote the employment of people with disabilities by establishing national goals. This recommendation was expanded upon by political appointees with disabilities throughout the Administration and ultimately became the executive order signed by President Clinton in March 1998.

As stated in the executive order, the purpose of the task force "is to create a coordinated and aggressive national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population." This high-level task force

includes Herman, Coelho, the secretaries of education, health and human services, treasury, commerce, transportation and veterans affairs, as well as the commissioner of Social Security, director of the Office of Personnel Management, chair of the Equal Employment Opportunity Commission, administrator of the Small Business Administration, and the chairperson of the National Council on Disability. The task force has been working in subgroups in preparation for a November 1998 report to the President. After it issues the report, the task force will begin to solicit input from the disability leaders on preliminary recommendations and further directions for the task force. Like the President's Initiative on Race (PIR), the Task Force on Employment of Adults with Disabilities provides an opportunity to educate all Americans about why people with disabilities have such low employment levels and what it will take to increase employment of this population. Equally important, the existence of the multiagency task force signifies that the issue of employment of adults with disabilities is not simply a matter of vocational rehabilitation but instead requires a systematic revamping of the public and private systems that children and adults with disabilities must navigate successfully to get and keep a job.

One system that must be navigated successfully to get to work is the transportation system. The Department of Transportation (DOT), which has been an active participant in the work of the Presidential Task Force on Employment of Adults with Disabilities, took an important step this past year to making intercity travel more accessible and affordable for travelers with disabilities when it issued its final rule on over-the-road bus accessibility. This requires every new bus purchased by a major carrier after the rule's effective date to be fully accessible for travelers in wheelchairs. The rule also requires full fleet accessibility over time as old buses are replaced with new ones.

Like transportation, home- and community-based personal assistance services must be available and affordable for working-age people who need assistance with activities of daily living to find and keep employment. With a well-attended March 1998 hearing on the Medicaid Community Attendant Services Act (MiCASA) in the Health Subcommittee of the Commerce Committee, Congress this year received eloquent testimony on the need for legislation that would provide real choices in the community for children, adults, and seniors who need long-term services and supports. This legislative effort also was buttressed by a July 1998 letter from

the Health Care Financing Administration (HCFA) to state Medicaid directors informing them of the ADA requirement that Medicaid-financed services, including long-term services, be provided in the "most integrated setting" appropriate. These two developments may be harbingers of broad-based efforts in the next Congress to eliminate the institutional bias in the current system and give people with disabilities and their families the ability to choose where to live and where to receive the long-term services and supports they need.

The return-to-work bills, President Clinton's Executive Order on Employment of Adults with Disabilities, the over-the-road bus regulations, the MiCASA hearing, and the HCFA letter all point toward progress in public policy; however, the last year also witnessed attempts to move the country backward by weakening civil rights protections for children with disabilities and their families under the Individuals with Disabilities Education Act (IDEA). Dissatisfied with the compromise on discipline that had produced sufficient votes to reauthorize IDEA in 1997, powerful members of Congress sought to amend the new law to make it even easier for schools to cease providing an education to children with disabilities in a wider range of circumstances. If these efforts had been successful, schools would have been given the opportunity to stop educating some students indefinitely without having to comply with any of the current due-process protections designed to ensure the schools' fairness and accountability.

Although the proposed amendments ultimately failed after intense opposition from parent and disability advocates, congressional supporters of IDEA, and the Administration, it is clear that many school boards, school administrators, and others involved in education policy believe that civil rights laws for children with disabilities are interfering with the ability of schools to maintain order and educate all students effectively. Outspoken school boards and their allies have fostered a climate where children receiving special education services are being scapegoated for all that is not working in American public education. If IDEA's critics are successful at further restricting the protections for children with disabilities beyond the compromise embodied in the 1997 law, the children who will suffer most will be those with disabilities with challenging behaviors, children from low-income families, racial and ethnic minority children, children in foster care, children in the juvenile justice system, and children living in rural areas without access to legal advocacy. These children are the most vulnerable to

unilateral disciplinary actions by schools because these children and their families often lack the financial resources and information to challenge unfair actions or to seek appropriate alternative educational placements. The weakening of civil rights protections in IDEA would be a tragic failure in American public policy for children and families. Moreover, if the proposed IDEA amendments are enacted, the negative impact of this change will be compounded by the recent elimination of Supplemental Security Income benefits for over 100,000 low-income children with disabilities and their families. In a period of economic prosperity, low-income families with children with disabilities are losing ground, while much of the society moves forward.

This report, which updates the progress report NCD issued in 1997, will describe significant policy developments in the last year and offer recommendations for the President and the 106th Congress.

PROGRESS, CONCERNS AND RECOMMENDATIONS

A. Disability Demographics and Disability Research

1. Demographics

The National Institute on Disability and Rehabilitation Research (NIDRR) at the Department of Education has published an extensive *Chartbook on Work and Disability in the United States, 1998*. The document is available in hard copy and is also excerpted on the World Wide Web.[1] The *Chartbook* draws upon data from several sources, including the Survey of Income and Program Participation, the National Health Interview Survey, the Current Population Survey, the decennial census, and the Annual Survey of Occupational Injuries and Illnesses. As noted in the *Chartbook*:

- Approximately 32 million people, or 18.7 percent of working-age Americans, report having some level of disability. Fifteen million people, or 8.7 percent of working-age Americans, report having a severe disability.[2]
- The *Chartbook* also reports statistics on the prevalence of disability by race and ethnic origin. Within the 18- to 69-year-old-age group, the following data are reported:

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[1] The Web site address is http://www.infouse.com/disabilitydata. The information contained there is excerpted from Stoddard, S., Jans, L., Ripple, J., and Kraus, L. (1998). *Chartbook on Work and Disability in the United States, 1998.* An InfoUse Report. Washington, D.C.: U.S. National Institute on Disability and Rehabilitation Research.

[2]Data reported last year by the U.S. Bureau of the Census based on Survey of Income and Program Participation results from 1994 indicated that 54 million people of all ages reported having a disability, 26 million of whom said that their disability was severe.

Ethnic Group	% Work Limitation	% Unable to Work
Native American	17.3	10.4
Black Hispanic	15.9	13.2
Black (non-Hispanic)	14.3	10.3
White (non-Hispanic)	11.6	6.2
White Hispanic	9.5	6.3
Asian or Pacific Islander[3]	5.7	3.4

- The *Chartbook* reports that there is little difference in the percentage of working-age men and women with a work disability. Approximately 8.4 million men, or 10.1 percent of the working-age male population, have a work disability. Approximately 9 million women, or 10.4 percent of the working-age female population, have a work disability. The *Chartbook* reports the following data:

Age Group	% Males	% Females	% Total Population
16-24	4.2	4.3	4.2
25-34	6.3	6.9	6.6
35-44	9.4	9.2	9.3
45-54	13.2	13.3	13.3
55-64	23.1	23.3	23.2
TOTAL	10.1	10.4	10.2

- The *Chartbook* reports that working people with disabilities have substantially lower monthly earnings than workers with no work disability, as follows:

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[3]Some researchers have pointed out that the relatively low rates of disability in the Asian Pacific Islander and Hispanic communities may stem from a reluctance of recent immigrants with disabilities in these groups to self-identify on surveys either because of unusually negative cultural associations with disability or because of fear of their disability status being used to undermine their ability to remain in the United States. See, for example, Leung, Paul. 1992. Asian Pacific Americans and Section 21 of the Rehabilitation Act Amendments of 1992. *American Rehabilitation*, 22(1): 2–6.

	Median Monthly Earnings	
	Men	Women
No Disability	$2,190	$1,470
Nonsevere Disability	$1,857	$1,200
Severe Disability	$1,262	$1,000

A 1996 *Chartbook* from NIDRR reports that 4.7 million children under age 18 have activity limitations (6.7 percent of all children).[4] The breakdown of activity limitation by age follows:

Percentage of Children, By Age, With Activity Limitations

	< 5	5-13	14-17
Limited in Nonmajor Activity	0.7	1.9	2.4
Limited in Major Activity	1.4	5.1	4.5
Unable to do Major Activity	0.6	0.6	0.7

2. Research Challenges

As the figures above demonstrate, the demographics of the disability community indicate that disability policy issues should be high priority issues for policymakers, given the size and scope of the community. As the disability community grows with the aging of the baby boom generation and as new disabilities emerge, disability policy will affect larger and larger numbers of the U.S. population. Although the employment rate of people with disabilities has received heightened attention in recent years, the employment rate for this population is not measured on a monthly basis in a manner comparable to women, blacks, and Hispanics. As part of the work of the Presidential Task Force on Employment of Adults with Disabilities, the Bureau of Labor Statistics is working with the U.S. Bureau of the Census, NIDRR, NCD and others to develop a methodology for measuring the employment rate of people with disabilities on a more regular basis.

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[4]Note that measurements of activity limitation in children do not capture the full range of impairment and disability in children. For example, many children served under the Individuals with Disabilities Education Act, particularly children with mental disabilities, may not show up on surveys that narrowly ask about activity limitations.

NCD is pleased that the federal research entities are working together to improve the timeliness and accuracy of demographic and economic information regarding children and adults with disabilities. And yet, as the demographic picture of the disability population becomes more sophisticated, there remain important challenges for the research community that transcend disability demographics. For disability data and research to meet the needs of policymakers, they must measure both the population of people with disabilities and the environments with which these individuals must interact.[5]

NCD encourages NIDRR to work with the federal research community to expand efforts to measure both the characteristics of people with disabilities and the characteristics of the environment. For example, what percentage of publicly financed town homes and single-family dwellings are visitable by people in wheelchairs? What percentage of public libraries have a text telephone available to deaf and hearing-impaired patrons? What percentage of federal agency Web sites are fully accessible for blind and visually impaired computer users? What is the average lead time required to obtain paratransit services? How many health maintenance organizations allow patients to see a specialist as their primary care physician? All of these questions have important policy implications, and they cannot be answered by looking at disability demographic information alone.

B. Civil Rights

At the 1996 NCD summit in Dallas, the issue of heightened enforcement of existing civil rights laws emerged as a consistent theme within many of the working groups. Although federal enforcement efforts have picked up since 1996, a need continues for stronger, more strategic, and more visible enforcement. Following up on the 1996 concerns about enforcement, NCD has undertaken a detailed analysis of federal enforcement of four civil rights laws: the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Fair Housing Act, and

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[5]For a more thorough discussion of this topic, see NCD's 1998 publication, *Reorienting Disability Research*, at http://www.ncd.gov.

the Air Carrier Access Act. These reports will be issued in the first session of the 106th Congress. In the following section and in the education, transportation, and technology sections of this report, NCD analyzes specific developments in civil rights law and policy during the period covered in this report. More detailed analyses of federal enforcement efforts will appear in the statute-specific reports NCD will issue in 1999.

1. U.S. Supreme Court Speaks on ADA

The United States Supreme Court heard its first two cases interpreting ADA in the last year. In the first case, *Bragdon v. Abbott*, the Court ruled that a woman who was HIV-positive but had not yet acquired symptoms associated with AIDS was nonetheless covered under ADA's definition of disability and thereby protected against discrimination when a dentist refused to fill her cavity in his office. *NCD applauds this result and encourages the Equal Employment Opportunity Commission and the Department of Justice to issue enforcement guidance using the Supreme Court's analysis to reiterate the appropriate way for courts to analyze whether a plaintiff in an ADA case is covered by the statute's definition of "disability." This guidance, coupled with the Supreme Court's decision in* Abbott, *should help to redirect the trend in lower courts that has narrowed the definition of disability to the point where people with breast cancer, epilepsy, diabetes, and mild mental retardation, as well as those who test positive for HIV, have been found to be outside ADA's protection.*

In the second case, *Pennsylvania Department of Corrections v. Yeskey*, the Court ruled that Title II of ADA did apply to state-run prisons. NCD applauds this result as well. In reaction to the *Yeskey* decision, some in Congress introduced a bill called the State and Local Prison Relief Act, which would have amended ADA and the Rehabilitation Act to exempt state and local agencies operating prisons from the civil rights requirements of the two laws. This bill was not enacted into law in the last Congress but may return in the new Congress. *NCD encourages the President and Congress to oppose any amendments to ADA or the Rehabilitation Act that would narrow the scope of protections they provide. Rather than mounting legal challenges to the constitutionality of Title II of ADA, as many states have attempted with limited success, the newly elected and incumbent governors and attorneys general at the state level should be*

expected to embrace the civil rights requirements of ADA and seek cost-effective ways to bring the instruments of state and local government into compliance.

Although the Supreme Court decisions in Bragdon *and* Yeskey *should help to correct some of the disturbing trends in federal court decisions under ADA, federal judges still need to develop greater understanding of the principles of ADA and other disability civil rights laws. This can be accomplished through continuing education programs for the bench. In addition, the President and Congress need to work together to find, appoint, and confirm qualified lawyers and judges with disabilities and with a good understanding of the legal and philosophical underpinnings of the disability civil rights movement to the federal bench.*

2. Hate Crimes

Congress acted this past year on the civil rights issue of hate crimes. On November 13, 1997, a Hate Crimes bill was introduced that would have increased the penalty for people convicted of hate crimes against people with disabilities. This bill did not ultimately pass, but another bill was enacted that requires the collection of data on the commission of hate crimes against people with disabilities. The data called for in the new law will make it easier to establish the need for legislation similar to the bill introduced in November 1997 and will help protect any such legislation from a constitutional challenge. *NCD commends Congress and the President for recognizing the need for the collection of data on hate crimes against people with disabilities and encourages the 106th Congress and the President to revisit this issue by passing a law that includes a stronger penalty and appropriate rehabilitation for people convicted of committing such crimes.*

3. Civil Rights Enforcement

a. U.S. Equal Employment Opportunity Commission (EEOC)

In part as a result of activities and recommendations associated with PIR, Congress approved a $37 million increase in the EEOC budget. This increase, the first significant budget increase for EEOC since it received the added enforcement responsibility of ADA, is an important first step toward giving EEOC the resources to investigate claims in a timely manner

and to provide badly needed outreach and technical assistance to its many stakeholders. *NCD commends Congress and the President for increasing EEOC's appropriations and encourages EEOC to use the increase to enhance customer service in the field and to train investigators on the quickly developing case law under ADA.*

b. Department of Housing and Urban Development

Also as part of PIR, the President proposed and Congress approved a significant expansion in the Department of Housing and Urban Development's (HUD's) fair housing enforcement budget for Fiscal Year (FY) 1999. The approved budget for fair housing programs was $40 million, up from $30 million in FY 1998. *NCD commends the President and Congress for recognizing the need to expand fair housing enforcement. NCD recommends that HUD use the increase in appropriations for fair housing to expand its enforcement of the Fair Housing Act and section 504 of the Rehabilitation Act on behalf of people with disabilities. To the extent that HUD will be doubling enforcement efforts under the Fair Housing Act, for example, NCD recommends that HUD's efforts under section 504 also be doubled.*

In early summer 1998, the Fair Housing and Equal Opportunity (FHEO) division at HUD amended its standard compliance review procedure to include, for the first time, a review for section 504 compliance as part of any fair housing compliance assessment. *NCD commends HUD for recognizing the need to integrate section 504 compliance monitoring within its generic fair housing compliance activities.*

In early 1998, HUD began a large-scale inspection effort, whereby it is systematically reviewing the physical plants of HUD-financed projects to assess compliance with many different safety and conservation standards. As part of this effort, HUD inspectors are assessing compliance with accessibility laws and regulations, such as section 504 of the Rehabilitation Act. *NCD commends HUD for doing this and encourages HUD to make the accessibility results public.*

In summer 1998, HUD's division of Policy Development and Research, along with FHEO, contracted with a private research firm to conduct a national survey of all newly constructed multifamily housing (with four or more contiguous units) built since March 1991 (the effective date of the Fair Housing Act's new construction guidelines). This survey will

gather data to provide statistically reliable information on the numbers, types and locations of buildings that do and do not comply with the Fair Housing Act. *NCD commends HUD for recognizing the need for comprehensive information in this area and encourages HUD to make the results of this survey public.*

In April 1998, HUD published a Fair Housing Guidelines Design Manual intended to further illustrate ways for buildings to comply with the new construction requirements of the Fair Housing Act. Some developers have pointed to the 1998 issuance of this document to argue that they should not be held liable for failing to comply with the Fair Housing Act's accessibility requirements for buildings that were built after the 1991 effective date of the law but before the 1998 guidelines. *NCD commends HUD for issuing these important guidelines and strongly encourages HUD to resist any efforts to eliminate liability for developers who built multifamily units between 1991 and the April 1998 publication of the Fair Housing Guidelines Design Manual.*

c. Department of Justice

Along with the EEOC and HUD increases, Congress approved an increase of a little more than $1 million for the Department of Justice's (DOJ's) Civil Rights Division to increase enforcement and mediation activities under ADA. *NCD commends Congress and the President for increasing the appropriation for ADA enforcement at DOJ. It encourages DOJ to expand its efforts to coordinate ADA enforcement across all the agencies, particularly in the areas of most integrated setting requirements under Title II; technology access issues under Titles II and III; and compliance by elementary, secondary, and postsecondary schools under Title II.*

4. Civil Rights Backlash

The backlash against civil rights for people with disabilities continued to show its face in the last year. Commentators and pundits continue to complain about the "wrong people" benefitting from ADA and about the extraordinary costs being incurred by employers, particularly for litigation. Critics argue that ADA is a failure because the employment rate for people with disabilities has not increased significantly since the law's passage and because of

the perception that the law is vague and difficult to interpret with certainty. None of these arguments withstand close scrutiny, yet they resurface consistently.

NCD encourages ADA enforcement agencies like EEOC, DOJ, and DOT to recognize that part of their mission as enforcement agencies must be to correct misperceptions or inaccuracies about ADA that only serve to feed the backlash. When an article is published that clearly misconstrues ADA, it is essential that the agency in the best position to respond does so in a timely and effective manner. If not, myths are allowed to disguise themselves as facts, and the environment for successful enforcement is compromised.

5. Access to the Electoral Process

The right to vote is one of the most fundamental civil and human rights in a democracy. Yet, many people with disabilities are not able to exercise this right fully because local elections are not accessible to them. In 1984, Congress attempted to resolve this problem by enacting the Voting Accessibility for the Elderly and Handicapped Act (VAA). Although this law was an important first step in recognizing and addressing voting access issues, it has not eliminated the widespread problems people with disabilities encounter with polling places and polling methods (e.g. voting booths and ballots). The law includes no effective remedy for individuals who are harmed by inaccessible polling places and fails to establish any national standard for accessibility.

Notwithstanding the weaknesses of VAA, some jurisdictions have been more proactive than others in ensuring access for voters with disabilities. In Rhode Island, for example, the state Board of Elections worked with the Governor's Commission on Disabilities to make 94 percent of the state's polling places accessible in time for the September 1998 primary elections. State officials also made provisions for assistance to individuals with disabilities who live in the inaccessible polling place neighborhoods.

NCD encourages the President and Congress to recognize that the ability of a person with a disability to vote should not depend on the goodwill of the state election agency but instead should be guaranteed as a federally protected civil right with real consequences when the right is violated. Accordingly, NCD encourages the President and Congress to enact

legislation that would amend VAA to recognize the right of all individuals to vote independently; guarantee accessibility to all stages of the electoral process (from voter registration to election day procedures); require the Architectural and Transportation Barriers Compliance Board ("Access Board") to establish standards for the accessibility of polling places, polling methods, and registration materials; strengthen the law's enforcement mechanisms to ensure private individuals are able to enforce their rights; and require regular and meaningful monitoring of access to elections for people with disabilities by the Federal Election Commission or other appropriate entity.

6. Wilderness Accessibility

Section 507(a) of ADA required that NCD identify important issues relevant to wilderness accessibility for people with disabilities. On December 1, 1992, NCD issued a report entitled *Wilderness Accessibility for People with Disabilities*, which included recommendations developed after a hearing and preliminary study of the issue. A key recommendation in the report was that the federal agencies responsible for wilderness management should better coordinate their policies and management practices regarding disability access and make them consistent with the requirements of federal nondiscrimination laws. In October 1997, a memorandum of understanding was signed by the federal wilderness management agencies and a nonprofit organization called Wilderness Inquiry, Inc. (WI), to coordinate their policies to "establish a general framework of cooperation between the agencies and WI for increased opportunities for people of all abilities to use and enjoy the programs, facilities, and activities of the agencies." In the last days of 105th Congress, related legislation was passed that requires the secretary of agriculture and the secretary of the interior to conduct a comprehensive study to improve the access for persons with disabilities to outdoor recreational opportunities (such as fishing, hunting, trapping, wildlife viewing, hiking, boating, and camping) made available to the public on the federal lands in the National Forest System, the National Park System, the National Wildlife Refuge System, and the Bureau of Land Management.

C. Education

1. Omnibus Fiscal Year 1999 Budget Bill

The final budget bill signed by the President included $1.2 billion for the first year of the President's initiative to hire 100,000 new teachers to reduce class size in the early grades to a national average of 18. This initiative is designed to help schools recruit high quality teachers and to insure that students receive more individual attention, a solid foundation in the basics, and greater discipline in the classroom. *NCD commends the President and Congress for providing funding to hire new teachers and reduce class size. NCD encourages the President and the Department of Education (DOE) to work to ensure that the new teachers have the proper training to meet the special needs of children with disabilities in mainstream classrooms. Moreover, NCD encourages the President and Congress to continue to work together to fund the hiring of additional new teachers in the upcoming FY 2000 budget discussions. Finally, NCD encourages the DOE to work to ensure that the new teachers hired as a result of the new funding represent a diverse cross-section of the communities they will serve, including people with disabilities. Teachers with disabilities, like teachers from other disenfranchised groups, represent important role models and can change school cultures with their example and their presence.*

The final budget bill also included new funding for after-school programs, child literacy, college mentoring for middle school children, education technology, child care quality, teacher recruitment, Head Start, charter schools, a Hispanic education initiative, Pell grants, and summer jobs. *NCD commends the President and Congress for investing in expanding programs aimed at children and youth. NCD strongly encourages the administering agencies for these new funds to ensure that the recipients of the funds take steps to include children and youth with disabilities in their activities. For example, the education technology funding should be spent on technology that is accessible for all students, including students with visual, hearing, learning and mobility impairments. Likewise, recipients of new charter school funding should be required to demonstrate their ability to serve students with a range of disabilities in mainstream settings.*

2. School Modernization

Having failed in the final days of Congress to prevail in his push for school construction funding, President Clinton likely will seek again to modernize public schools around the country by using tax credits to leverage nearly $22 billion in bonds to build and renovate schools. *NCD strongly supports the President's initiative to modernize our schools. It encourages the President and Congress to work together to find the funds to support this initiative, and then to ensure that the newly built or renovated schools are models of universal design so that all students, teachers, and parents will be able to participate fully in all aspects of the schools of the future.*

3. IDEA Proposals

Less than five months after the IDEA Amendments of 1997 (IDEA 1997) were signed into law on June 4, 1997, DOE issued a Notice of Proposed Rulemaking (NPRM) inviting public comment on the proposed regulations by January 20, 1998. As of October 31, 1998, no final regulations had been issued. An achievement of bipartisan compromise, the enactment of IDEA 1997 followed months of intense political struggle to block reauthorization. As noted in the introduction to this report, the struggle resurfaced this year in a flurry of measures in the House and Senate designed to block or to erode key provisions of the law. These amendments, summarized later, have sought to limit the civil rights protections of IDEA in the name of greater flexibility for schools.

Several amendments proposed changes affecting due-process protections in the administration of school discipline procedures. Current law allows removal of students to an interim alternative educational setting (IAES) for up to 45 days at a time only when they bring a weapon to school, commit a drug-related offense at school, or have been found by an independent hearing officer to be substantially likely to injure themselves or others. One amendment, referenced in the Introduction, proposed to allow schools to remove unilaterally students who intentionally exhibit violent behavior that has, or could have, resulted in injury to themselves or others, even if the behavior was a manifestation of the disability. The amendment would have replaced objective decisionmaking by an impartial and independent hearing officer

with unilateral fact-finding and decisionmaking by the school. Finally, this amendment proposed to delete the 45-day limit on exclusion of students from their regular classroom, which would eliminate protection against indefinite removal without review. A more extreme variation on this amendment would have provided that, notwithstanding IDEA, state and local educational agencies could establish and implement uniform discipline policies applying to all children within their jurisdictions. School personnel would be permitted unilaterally to expel children with disabilities whose behavior was disruptive, even if related to their disability, regardless of any IDEA provision.

A second provision targeted for amendment was the right to educational services for youth with disabilities incarcerated as adults. The proposed amendment in this area would have made it impossible for DOE to reduce or withhold payments from states for failure to provide special education and related services to these children after age 18. As proposed, this provision would have effectively eliminated access to appropriate educational services by young prisoners in many states.

Finally, IDEA provides for the payment of attorneys' fees to parents who are prevailing parties in actions or proceedings brought under section 615 of the Act. Language imbedded in the House District of Columbia appropriations bill would have: 1) eliminated attorneys' fees for administrative hearings, which make up the bulk of special education cases, and 2) limited attorney compensation to $50/hour for cases filed in court, with a cap of $1,300 per case.

Each of these amendments directly challenged the core premises of IDEA—that each child with a disability has the right to a free appropriate public education (FAPE) in the least restrictive environment consistent with that goal, has due process protections against unilateral actions by the school, and has access to an effective remedy when schools fail to comply with their obligations. After a fierce battle, the discipline amendments were dropped in exchange for a nine-month study of the effect of federal special education protections on the ability of schools to maintain discipline. This study will be conducted by the U.S. General Accounting Office. All of the other amendments were dropped, except the cap on attorneys' fees in the District of Columbia, which remained in the final appropriations bill approved by Congress. Many fear that the D.C. measure is the trial balloon for a broader attempt to cap attorneys' fees, which would

make it even less likely that a family with a child with a disability would be able to assert their legal rights in court.

Advocates devoted significant energy and resources this year to opposing these attempts to weaken the law and encouraging DOE to strengthen the proposed regulations and issue the final regulations as quickly as possible. While the NPRM mirrors or strengthens the provisions of IDEA 1997 for the most part, significant weak areas remain. Among them are temporary suspension of educational services following short-term removal from the classroom, lack of specific timelines for completing important actions, unclear requirements concerning the notification and inclusion of parents in key meetings and decisions, and only partial inclusion of requirements for the early intervention program (Part C). After receiving thousands of comments on the NPRM, DOE moved the release date for the final regulation from late spring to December 1998.

NCD recommends that the DOE promptly issue the final regulations implementing IDEA 1997. The regulations will serve as both a safeguard and guidance to the educational system at state and local levels. NCD strongly encourages local jurisdictions to use the federal regulation as a model in developing their own guidelines for implementing IDEA and incorporating best practices drawing on their local successes.

Along with opposition in Congress and concomitant delays at DOE, IDEA continues to be met with noncompliance and outright opposition at the state and local level. Feedback from national parent networks indicates that opposition to IDEA and the protections it affords arise from five core perceptions: 1) students with disabilities require more than their fair share of educational resources, which makes it more difficult for schools to educate the rest of their students; 2) the unfettered ability of schools to exclude children with challenging behaviors is necessary to ensure school safety; 3) IDEA paperwork requirements (i.e. the Individual Education Plan [IEP]) divert resources from educating children; 4) IDEA imposes requirements that take away control from state and local education agencies, and 5) schools do not want to deal with difficult children in mainstream settings.

Parents around the country report strong resistance on the part of school personnel and administrators to providing appropriate services for their children. At the same time, powerful

education associations lobby to give local school personnel authority to cease education for students with disabilities without due process. In many school districts, parents must continually fight for services required by IDEA, which indicates that noncompliance may be widespread and largely unchallenged.

NCD recommends that DOE and DOJ recognize and correct the inadequacy of current federal compliance monitoring activity. School systems that fail to provide services required under IDEA are compromising the futures of children with disabilities. Federal authorities must develop more effective monitoring mechanisms to identify and challenge failures to comply. School systems found not in compliance must be held accountable for correcting deficiencies within specified time frames or face sanctions. Where the will to fully implement IDEA is lacking, sanctions must be applied in combination with positive incentives to change resistance to definitive action.

Providing all children access to FAPE requires many changes to our existing educational systems. Rather than expecting all children to achieve on the same terms, FAPE requires collaboration between parents and school personnel in accommodating the needs of individual children. It requires a systematic approach to supporting each child's individual ability and excellence, which means an alternative approach to the allocation of educational resources. It requires acquiring and integrating assistive technologies into the classroom that have not been available previously. It requires drawing on expertise from a variety of sources, rather than expecting one educator to address all the needs of a child with a disability. Implementing IDEA requires a commitment to change, as well as an increase and a reallocation of resources at the national, state, and local levels.

Federal policy must support solutions aimed at directing resources toward creating safe and inclusive educational environments; thorough, yet manageable, information management systems; and collaboration between parents and state and local school personnel in meeting the educational needs of all students.

NCD recommends that the President and Congress make good on the 1975 commitment to allocate to the states 40 percent of the funding needed to implement IDEA. This year Congress approved funding at 12 percent, which is the highest level yet, but still far short of

what is needed. Also, in light of the fact that the federal government has increased its share of funding for IDEA by approximately $1.5 billion over the last three years, NCD encourages the DOE to assess what local schools have been able to accomplish with these additional funds. Are teachers receiving better training in ways to meet the needs of children with disabilities? Have early intervention programs been expanded for infants and toddlers with disabilities? Are funds being used to empower parents of children with disabilities by providing parent training and information about IDEA?

NCD recommends that state education agencies assist local school systems in organizing, simplifying and standardizing IDEA's information requirements to make compliance easier and to develop meaningful data for measuring results.

Finally, NCD urges educators across the country to view IDEA as a national commitment to educating all children, regardless of their circumstances, and to accept the challenge of reshaping their local education systems to be responsive to the needs of individual students. Developing collaborative models for interaction between parents, school personnel, and students will be a key strategy in creating this responsiveness and removing the barriers to FAPE for all students with disabilities.

4. Charter Public Schools

The Administration has been generally supportive of charter public schools as a laboratory for innovation in American public education. As previously noted, the final budget bill included increased federal funding for public charter schools. The Administration and many in Congress have indicated a desire to see charter schools continue to grow in number with federal support.

NCD is concerned that public charter schools are being created in some jurisdictions without actually ensuring that the teachers and administrators are prepared to comply with IDEA, ADA and section 504 of the Rehabilitation Act when children with disabilities seek to enroll. NCD encourages DOE to provide technical assistance, oversight, monitoring, and enforcement to the growing number of charter schools in best practices for educating students with disabilities.

5. Elementary and Secondary Education Act

One of the items on the agenda for the 106th Congress will be the reauthorization of the Elementary and Secondary Education Act (ESEA), an important law that sets out federal education policy for all students, particularly students from low-income families. ESEA currently requires states to set high standards for all students, to create quality assessments that measure how well students are meeting those standards, and to create an accountability system for schools to ensure that schools are making progress toward preparing students to meet the standards. Under ESEA, schools must provide an enriched and accelerated curriculum, effective instructional methods, high-quality professional staff, high-quality professional development, and timely and effective individual assistance for students who are struggling to meet standards. Schools must meet all of these elements in a program developed in partnership with parents.

NCD encourages the President and Congress to take advantage of the opportunity provided by the ESEA reauthorization to address the need for mainstream education policy to integrate the needs of students with disabilities and students from low-income families so that the educational outcomes of all students may be improved. For example, NCD encourages the President and Congress to use the reauthorization to ensure that students with disabilities are meaningfully included in standards-based reform and expected to meet high standards, with appropriate accommodations; to expand parent training and information efforts by building upon and promoting linkages with community-based parent training and information centers funded under IDEA, so that all parents can work together to promote high-quality programming that meets the individual needs of all students; and to improve teacher training and professional development to better meet the diverse needs of students in mainstream settings.

6. Education of the Deaf Amendments of 1998

As part of the Higher Education Amendments of 1998 passed by Congress and signed by the President, the Education of the Deaf Act was amended to require elementary and secondary programs to comply with certain requirements of IDEA, among other things. The legislation also requires the secretary of education to study and report to Congress on the education of the deaf to identify those education-related factors in the lives of deaf individuals that result in

barriers to successful postsecondary education experiences and employment, or contribute to successful postsecondary education and employment experiences. *NCD commends the President and Congress for recognizing the importance of conducting a thorough study of the factors in public education of deaf students that impede or promote their success after secondary school, and encourages the secretary of education to act promptly to complete the study and report.*

D. Health Care

1. Protections in Managed Care

Like the education system, the health care system is an essential infrastructure that can either facilitate functional ability and choice for people with disabilities or make it difficult for people with disabilities to achieve their goals. With the vast majority of people in private insurance and a growing percentage of the Medicaid population enrolled in managed care, people with disabilities have a strong stake in the efforts to create rights for patients in managed care systems. In the last year, the President and many in Congress worked to pass a "patient's bill of rights," which would include patient protections such as assuring access to specialists; creating strong emergency room protections; continuity of care provisions to prevent abrupt changes in treatment; a fair, timely, and independent appeals process for patient grievances; and enforcement provisions to make these rights real. *NCD strongly encourages the President and the 106th Congress to overcome partisan differences and work together to forge a strong, enforceable bill that will give patients with disabilities and their families sufficient protections to ensure that they have access to the quality health care they need. In addition, NCD recommends that the President and Congress work together to address the unique issues managed care has created in medical rehabilitation, where people with disabilities are being forced to leave rehabilitation hospitals prematurely and are not receiving the range of necessary services and supports that medical rehabilitation professionals provided before the growth of managed care.*

2. Medicare Reform

Another big item on the health care agenda is the future of the Medicare program. Much like the debate on Social Security solvency, the discussions around the future of Medicare have largely taken place with little or no involvement by people with disabilities. Despite the fact that many working-age people with disabilities rely on Medicare and the health care provided along with their SSDI benefits, this population has been virtually ignored in the Medicare discussions to date. *NCD encourages the President, Congress, and the Bipartisan Commission on the Future of Medicare to involve people with disabilities and their advocates in the discussions about what should happen with the Medicare program. At a minimum, the commission should reach out to working-age Medicare enrollees with disabilities to obtain their input on how the program might better meet their needs. As it stands currently, Medicare is much more effective for elderly enrollees than it is for working-age people with disabilities because it is structured with the needs of the elderly in mind. To the extent that changes are being considered, NCD encourages the President and Congress to consider making the scope of coverage under Medicare more in line with the kinds of services and supports needed by working-age people with disabilities.*

3. Medicaid Buy-In

In 1997, NCD reported on the provision in the Balanced Budget Act of that year that created an optional program whereby states could allow people with disabilities who were earning up to 250 percent of poverty to purchase Medicaid coverage. This past year, HHS Secretary Donna Shalala personally wrote to every state to encourage implementation of this provision. To date, NCD is aware of only one state, Oregon, that has taken advantage of this option. Oregon amended its state Medicaid plan, with approval from HCFA, and is in the process of writing its administrative rules and implementation procedures. The Oregon program will be similar to section 1619(b) but offers Medicaid to working individuals who have unearned income, higher income levels, and others. The program will let individuals go to work and get and keep Medicaid, even if their income exceeds $40,000. *NCD commends Oregon for being the first state in the nation to take advantage of the 1997 Balanced Budget Act provision and*

encourages other states to follow Oregon's lead and expand health care options available to their populations of people with disabilities when they are working.

4. Assisted Suicide

On another front, this year witnessed an attempt in Michigan to follow Oregon's lead in legalizing physician-assisted suicide. Although it acknowledges differences of opinion in the disability community on this topic, NCD opposes legalization of physician-assisted suicide because of the real danger that this practice, if made legal, will be used in a discriminatory manner against individuals with disabilities. As of October 31, voters in Dr. Jack Kevorkian's home state were poised to reject a measure that would have made Michigan the second state with legalized physician-assisted suicide.

The measure, known locally as Proposal B, was headed for defeat according to the polls, which in weeks before the election showed support eroding under a mult-million-dollar advertising campaign by well-funded opponents, including the Michigan State Medical Society, the Roman Catholic Church and Right to Life of Michigan. Disability rights groups, particularly Not Dead Yet, also were vocal in their opposition to the measure.

Opposition also came from Kevorkian, who says he has attended more than 120 deaths but considered Proposal B too restrictive and regulatory. He called the proposal "crazy."

The measure would have allowed doctors in some cases to prescribe a lethal dose of medication for terminally ill patients wishing to kill themselves. It got on the ballot through an effort by Merian's Friends, a group named after a woman who died with Kevorkian's involvement.

NCD commends the voters in Michigan for recognizing the problems inherent with the legalization of physician-assisted suicide, and encourages the President and Congress to speak out against this dangerous and unnecessary expansion of the physician's role. Health care should be about healing, not killing.[6]

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[6]For a thorough discussion of assisted suicide from a disability perspective, see NCD's 1997 publication *Assisted Suicide: A Disability Perspective*, available on our Web site at http://www.ncd.gov.

Another important development in this area occurred in Congress. In response to the failure of DOJ to take action against physicians prescribing lethal drugs under federal controlled substances laws, some in Congress introduced the Lethal Drug Abuse Prevention Act of 1998. Although the bill was not enacted, it did receive a hearing before the Constitution Subcommittee of the House Judiciary Committee. Diane Coleman from the disability rights group Not Dead Yet testified at the hearing. *NCD commends the Constitution Subcommittee for recognizing the importance of including a disability rights perspective in discussions about assisted suicide, and NCD encourages the President to work with Congress to craft a federal law that will protect the human rights of people with disabilities and restrain the ability of physicians to prescribe lethal drugs.*

E. Long-Term Services and Supports for Individuals and Families

A necessary corollary to an effective acute care system is an affordable system for long-term services and supports for individuals and families. The biggest problem with the current system from the perspective of children and adults with disabilities and their families is the lack of real choices it offers people in need of long-term supports. Because of the institutional bias in the Medicaid statute, where nursing home care is mandatory in every state but home- and community-based care is optional, approximately 80 percent of the funding for long-term services and supports goes to services in institutions. This continues to occur notwithstanding the fact that the vast majority of people with disabilities of all ages and their families would prefer that the services be delivered in home- and community-based settings.

1. Federal Legislative Efforts

As mentioned in the Introduction to this report, in March 1998, the House subcommittee with jurisdiction over Medicaid held a hearing on MiCASA, which was developed with the disability rights group ADAPT and attracted many sponsors on both sides of the aisle. Approximately 50 national disability and aging groups have indicated their support of MiCASA. At the hearing, Speaker Newt Gingrich and Minority Leader Richard Gephardt both testified

eloquently about the need for legislation that would enable people with disabilities to choose to live outside of nursing homes and other institutional settings, and many witnesses presented compelling testimony about the institutional bias in the current system and the failure of federal and state policy to honor the "most integrated setting" goals articulated in ADA for delivery of state and local services. Nonetheless, very little happened in the last Congress that moved the ball forward on national legislation to remove the institutional bias in the Medicaid system. Senator Russell Feingold's bill, modeled on the long-term care provisions of President Clinton's Health Security Act, likewise received little attention from the Finance Committee in the Senate, which is the committee of jurisdiction. *NCD encourages the 106th Congress to move beyond rhetoric and implement a strategy for dramatically expanding consumer choice in long-term care. As the population ages, the crisis currently being felt among many seniors and people with disabilities who require assistance with activities of daily living will only become more widespread.*

2. Administration Efforts

On a more positive note, the Administration took steps in the last year to call attention to ADA's requirement that home- and community-based services, like other government-funded services, be delivered in the "most integrated setting" appropriate so that people with disabilities do not receive services in segregated settings unnecessarily. As Attorney General Janet Reno said before the National Council on Independent Living in May,

> *We believe that states have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. And we have used the law to fight for this. Many individuals with disabilities are being placed in nursing homes or other institutional settings even when they don't really need to be there.*

On a similar note, Sally Richardson, who directs the Medicaid program for HCFA, issued a directive to state Medicaid directors in conjunction with the ADA anniversary at the end of July that pointed out ADA's requirement that state and local services be delivered in the most integrated setting appropriate to the service. *NCD commends the President; Secretary Shalala; Nancy-Ann Min DeParle, administrator of HCFA; Sally Richardson, director of the Center for*

Medicaid and State Operations at HCFA; and Robert Williams, deputy assistant secretary for disability and long-term care policy at HHS, for working together to issue the directive to Medicaid directors regarding ADA's implications in the area of Medicaid services. NCD also encourages HCFA to stand firm behind its letter and resist state efforts to read the letter in a manner that enables them to deliver services in the same manner to which they have grown accustomed. NCD encourages HHS to provide technical assistance to states on how to comply with the most integrated setting requirement in the Medicaid program. At the same time, NCD encourages the Administration to fund an initiative as part of its FY 2000 budget that will enable states to transition from a system that focuses on institutions to one that focuses on home- and community-based services.

3. Family Support

Like adults with disabilities, many families of children with disabilities have advocated for long-term services and supports for their children and for family caregivers to enable families to care for their children at home and outside of institutions. In 1994, Congress created a new part in the Individuals with Disabilities Education Act which authorized HHS to fund state efforts to promote systems change at the state level that would enhance services and supports for families of children with disabilities. This authorization effectively expired on October 1, 1998, without being reauthorized. However, President Clinton inserted and Congress approved a line item in the FY 1999 budget that allocated $4 million for family support. These funds will be used to support 17 competitive grants to conduct projects of national significance in the area of family support. Accordingly, for the first time, the President and Congress have recognized the need to fund a family support program for families of children with disabilities. *NCD commends the President and Congress for allocating funds to support systems change at the state level that will enhance the ability of families to care for their children at home and outside of institutions. At the same time, NCD encourages the President and Congress to reauthorize in statute an ongoing family support program administered by HHS, possibly as part of the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.*

4. Child Care

In the omnibus budget bill approved at the end of the 105th Congress, the Child Care and Development Block Grant (CCDBG) received $172 million specifically to promote quality in the delivery of child care services. This money has been used in the past and can be used in the future for technical assistance activities to support best practices in the area of inclusion of children with disabilities in mainstream child care programs. In addition, Congress and the President supplemented the budget for after-school care by $140 million. This money may be used to expand the availability of after-school programs for all children, including children with disabilities. *NCD commends the President and Congress for making available funds to improve child care options for children with disabilities and their families. NCD encourages HHS and DOE to work with the states and local governments to ensure that children with disabilities are integrated into the child care and after-school care networks developed with the new funding. Also, in light of the fact that 24 states currently have waiting lists for children to get into quality child care programs, NCD encourages the President and the 106th Congress to continue to expand the federal commitment to ensure that all children have access to quality, affordable, accessible child care.*

F. Immigrants, Racial and Ethnic Minorities with Disabilities

NCD has worked for many years to address the unique needs of minorities with disabilities in our policy work. Recently, NCD has hosted roundtable discussions and hearings in Atlanta, New Orleans, and San Francisco on the issues facing people with disabilities from minority and rural communities from different sections of the country. On October 1, 1998, NCD released a report capturing input from the January 1998 hearing in New Orleans focused on children and youth with disabilities and their families from minority and rural communities in Louisiana.[7] The report included suggestions and recommendations on a range of issues,

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[7]The report, entitled *Grassroots Experiences with Government Programs and Disability Policy*, is available from NCD's Web site at http://www.ncd.gov.

including education, vocational rehabilitation, juvenile justice, access to medical services, independent living, family and individual support, and community participation. Early in 1999, NCD will issue a report that captures input from its hearing in San Francisco in August 1998. NCD is eager to work with the President and Congress to redouble federal efforts to tailor federal policies and programs so they appropriately address the unique issues facing people with disabilities from minority racial and ethnic communities.

5. President's Initiative on Race

Over the past year PIR has sponsored research and discussions around the country to facilitate education and cooperation on race issues in America. In September, the PIR Advisory Board presented to President Clinton its final report, which details the activities undertaken and the policy recommendations developed to reduce social and economic division by race. Although minimal attention was given to race issues related to disability (including cosponsorship with NCD of an August discussion involving community leaders in San Francisco), overall the effort to hear from and comment on the unique issues facing minorities with disabilities has been inadequate, and significant opportunities have been missed. *NCD hopes that the President will seek to remedy the situation in his expected report to the American people based on this initiative.*

Research studies, including the National Health Interview Survey statistics previously cited, consistently show that people from diverse cultural communities experience higher rates of disability as a result of living conditions such as poorer health care coverage, greater exposure to violent crimes, nutrition issues, and increased presence of environmental pollutants. The problems resulting from higher rates of disability are compounded by weaker disability support systems, including education and employment settings that are less informed and equipped to address accessibility needs of people with disabilities. Accordingly, it is in the interest of racial and ethnic minorities, at least as much as others, to advocate public policies and resources that promote the personal independence, social integration, and economic empowerment of Americans with disabilities.

In addition to the problems faced by people with disabilities of all races, some particularly affect people who are members of racial and ethnic minority groups. Navigating the immigration and naturalization process, for example, can be harder when one has a disability that affects one's ability to learn English through standard instructional methods, affects one's capability to give fingerprints (a man without fingers has had his naturalization delayed for years because of this problem), or affects one's capacity to give the oath of allegiance. Despite the fact that civil rights laws protect immigrants with disabilities against rigid application of citizenship requirements, NCD has heard numerous individual reports of the Immigration and Naturalization Service's refusal to make accommodations. Another example is that some cultures have not yet developed language about disability that makes it acceptable to self-identify, request, and receive government interventions such as civil rights enforcement and rehabilitation services. Through dialogues and research in conjunction with the disability community, PIR could have advanced understanding in these areas and helped to encourage more enabling policies and practices for minorities with disabilities.

NCD does commend PIR for recognizing in its report a pattern at the local level of giving special education labels to children with disabilities from minority backgrounds, which results in many of them being unnecessarily stigmatized and separated from mainstream education settings. Regulations to be issued by DOE implementing the IDEA Amendments of 1997 can and should correct this practice. NCD also praises the President's action in July to direct key federal civil rights agencies to increase their outreach and implementation efforts in diverse cultural communities. *NCD urges federal civil rights enforcement agencies to work together to develop culturally competent models for outreach and training on federal civil rights laws and procedures in minority racial and ethnic communities.*

2. Health-Related Funding in Minority Communities

In the final budget bill that passed at the end of the 105th Congress, $150 million was included to address HIV/AIDS issues in minority communities. This investment will be used to improve prevention efforts in high-risk communities and expand access to cutting-edge HIV therapies and other treatment needed for HIV/AIDS. In addition, Congress approved the

Administration's request to fund grants for communities to develop new strategies to address disparities in prevalence of diseases between minority and white populations. Among African Americans under the age of 65, for example, the rate of heart disease is twice the rate among whites in that age group. As another example, Native Americans have an incidence of diabetes nearly three times the national average. As part of the President's initiative to eliminate racial health disparities, Congress also approved increases in other public health programs, such as heart disease and diabetes prevention at the Centers for Disease Control, that have proven effective in attacking these disparities. *NCD commends the President and Congress for recognizing the need to pay particular attention to disability issues in minority communities. As the President and Congress continue to build on these first steps, NCD encourages them to address the dramatic disparities in labor force participation between minorities with disabilities and others.*

G. Social Security Work Incentives and Social Security Solvency

1. Work Incentives

As mentioned in the Introduction, this Congress saw significant progress toward making it easier for people receiving Social Security disability benefits to go back to work, but ultimately no bill was passed by both houses of Congress. On September 24, 1997, NCD presented the President and Congress with a list of action proposals to remove barriers to work.[8] The proposals, which were developed after broad consultation with people with disabilities, their families, advocates, and policy experts around the country, included actions that would "make work pay" by providing medical coverage for workers with disabilities, replacing the SSDI income cliff with gradual benefit reductions, ensuring that people would not lose eligibility solely because they work, compensating for disability-related work incentives, and other items. The NCD recommendations also supported the creation of a ticket or voucher program that

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[8]National Council on Disability, *Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond*, September 24, 1997.

would enable SSI recipients and SSDI beneficiaries to select and buy services leading to employment and the creation of a financial reimbursement mechanism for employers who encounter costs for certain extraordinary accommodations.

On June 4, 1998, the House voted 410-1 to pass the Ticket to Work and Self-Sufficiency Act. This bill would have instituted a ticket program similar to the NCD proposal designed to increase consumer choice in vocational rehabilitation. It also would have authorized a demonstration project in which a select group of beneficiaries would have lost cash benefits at a rate of one dollar for every two dollars they earned over an amount to be determined by the commissioner of Social Security. The House bill did not include the national two-for-one proposal espoused by NCD because that proposal had received a large score from Congressional Budget Office and the actuaries at SSA, both of which were concerned about people being induced by that benefit to come onto the rolls.

The Work Incentives Improvements Act in the Senate included a ticket component similar to NCD's and the House bill and included a demonstration program for the two-for-one similar to the House bill. In addition, it included significant health care protections for SSI and SSDI beneficiaries that would have enabled them to keep their health care when they returned to work. Another important component of the Senate bill was the definition of personal assistance services that would have been part of the health coverage—a definition that included readers and personal assistance with transportation to and from work. Finally, both the Senate and House bills included provisions that would have prevented the Social Security Administration from punishing people who try to work by instituting a continuing disability review.

An important consensus that emerged as the 105th Congress drew to a close was the realization that the disability community was not interested in a work incentives bill that did not include a significant health care protection for people trying to leave the Social Security rolls. Because the health care component was significantly more costly than the other components of the legislation, it was necessarily the most difficult to achieve. *NCD encourages the President, commissioner of Social Security, and Congress to build on the progress made last year and pass a work incentives bill that includes basic access to health care and expanded choice in rehabilitation providers for consumers similar to the Work Incentives Improvements Act. NCD*

encourages the Administration and Congress to fund the health care components of the bill at a level that will make them sufficiently attractive for states to choose to participate.

2. Social Security Solvency

As mentioned in the Introduction, people with disabilities have not played a large or visible role in discussions about the solvency of the Social Security Trust Fund to date. Accordingly, many Americans have a perception that Social Security is only for people who have retired, and the debate about solvency has centered almost exclusively on Social Security retirement. Yet, the reform efforts that will play out in the 106th Congress will have a dramatic impact on the people with disabilities who depend on SSDI benefits to survive. More than one-third of all Social Security benefits are paid to nonretirees: people with disabilities, children, and widowed spouses. For the average wage earner with a family, Social Security insurance benefits are equivalent to a $300,000 life insurance policy or a $200,000 disability insurance policy.

As the debate moves forward, NCD encourages the President and Congress to:

- *ensure the meaningful inclusion of people with disabilities and their families in discussions about the projected shortfall of the Trust Fund;*
- *preserve the guarantees inherent in the disability insurance program and the protections for survivors and dependents in the Old Age, Survivors, and Disability Insurance programs of Title II of the Social Security Act;*
- *protect the integrity of the benefits provided so that they are at a reasonable level for support and protect the value of the benefits so that the buying power of the benefits does not diminish with inflation; and*
- *take into account any potential effect on the Supplemental Security Income program when assessing the impact of any reform proposal. For example, if there are reductions in benefits for retirees and people with disabilities, under current law, the SSI program would have to step in to support many of those who would be forced further into poverty.*

H. Employment

1. Job Training and Vocational Rehabilitation

On August 7, 1998, the President signed the Workforce Investment Act (WIA), which included the Rehabilitation Act Amendments of 1998. In the WIA, the employment and training provisions and adult literacy provisions specifically require that people with disabilities be considered a priority population for service delivery. *NCD commends Congress and the President for requiring the mainstream employment, training and literacy systems to prioritize service delivery to people with disabilities. This will enhance the likelihood that people with disabilities leaving the Temporary Assistance for Needy Families (TANF) rolls and the SSI/SSDI rolls will be able to access the services they need to obtain and retain competitive employment.*

NCD also commends congressional leaders who made the process of reauthorizing the act bipartisan and inclusive of the disability community. NCD praises Congress and the Administration for establishing better links between the vocational rehabilitation (VR) system and the general work force development system through this law. Jobseekers with disabilities will have improved options for service through the mainstream worker training and placement system, as well as through the disability-specific VR system. The U.S. Department of Labor has been providing valuable technical assistance to the network of one-stop career centers on how to provide nondiscriminatory and accessible services to people with disabilities. *While these preliminary efforts are a good start, the mainstream employment and training networks should implement a comprehensive training module so that line staff are well informed about resources available for people with disabilities seeking employment and are well equipped to meet the needs of clients with a wide range of disabilities.*

Perhaps the best improvement to the Rehabilitation Act in the WIA is the considerable strengthening of section 508, discussed in detail later in the technology section of this report. The U.S. Access Board has begun to develop the accessibility regulations, which are expected to have a major impact on the market availability of accessible technology, as industry designs products to meet federal procurement requirements.

Some other improvements to the Rehabilitation Act are worth noting. The Individual Plan for Employment (IPE) is the new term for the Individualized Written Rehabilitation Program (IWRP), which gives more control to consumers in developing their VR plan for services. VR plans may now be developed by the individual or an outside advocate, as long as the document is signed by a qualified rehabilitation counselor. The language is strengthened concerning the obligation of state VR agencies to offer informed choice to clients about service alternatives available to them, including those provided by other organizations both inside and outside the state. Trial work experiences are encouraged as a way for agencies to evaluate whether potential clients will benefit from VR assistance. States with an order of selection policy—by which persons with more severe disabilities receive priority for assistance—are nonetheless expected to provide core information and referral services to all people with disabilities who contact the agency within the state. Mediation is encouraged as an approach to resolving client-agency disputes without compromising the right to formal adjudication. The Rehabilitation Council, formerly Rehabilitation Advisory Council, has more of a role in developing agency policies and plans.

The Rehabilitation Act Amendments of 1998 were nonetheless disappointing in not going further in some areas. *The illogical division between the administration of VR services to people with visual disabilities and all other disabilities was not addressed. Stronger and more considered efforts should have been required to meet the needs of traditionally underserved populations, including people from diverse cultural communities, individuals with psychiatric disabilities, and residents of rural areas such as Indian reservations. State rehabilitation councils should have been given sign-off authority analogous to that which statewide independent living councils have on independent living plans. Client Assistance Programs should have been required to be independent from state VR agencies so they can advocate effectively from outside the VR system.*

In summary, the 1998 reauthorization of the Rehabilitation Act made some significant improvements but passed up an opportunity to make some important additional reforms. *NCD encourages the Rehabilitative Services Administration to work closely with the Presidential Task Force on Employment of Adults with Disabilities to develop bold, multiagency demonstration*

and research initiatives to achieve dramatically better outcomes in employment rates for people with disabilities, and to provide the policy options for a truly revolutionary reauthorization of the Rehabilitation Act that encompasses responses to the range of disincentives that have prevented people with disabilities seeking employment from succeeding. Moreover, NCD encourages the President and Congress to recognize that the VR program has received level funding for years and will require additional funding to adequately address the needs of people moving from welfare to work and from Social Security disability programs to work.

2. Presidential Task Force on Employment of Adults with Disabilities

As mentioned in the Introduction, President Clinton signed an executive order in March 1998 creating a task force chaired by the secretary of labor to develop policy recommendations for the President to bring the employment rate of adults with disabilities as close as possible to the level of the rest of the population. During the period covered in this report, the task force met twice and created a series of work groups to address specific employment topics listed in Section 2 of the executive order. A report including the outcome of the work group efforts and recommendations to the President was under development as the period covered by this progress report came to a close.

NCD commends the President for seeing the need to pull together a broad array of federal cabinet secretaries and agency heads to address what is clearly a multidimensional and challenging issue. As the work of the task force moves forward, NCD encourages the task force to recognize that some of the biggest barriers to employment for people with disabilities include work disincentives in our public benefit systems; the lack of accessible, affordable home- and community-based long-term services and supports; inadequate housing and transportation infrastructures; and a lack of educational credentials and work experience in the target population. Moreover, as long as students with disabilities drop out of high school at a rate twice that of their nondisabled peers, we will continue to see disappointing employment outcomes for young people with disabilities. Likewise, the unique needs of racial and ethnic minorities with disabilities in both the education and job training and rehabilitation systems

must receive special attention so that the task force will reach the full population of adults with disabilities.

In short, NCD encourages the task force to take the opportunity the President has provided to develop broad-based, cross-cutting initiatives that will fundamentally alter the landscape of public policy for Americans with disabilities. The problem the task force has been asked to address will be solved only with dramatic, visionary approaches. Incremental tinkering with existing programs simply will not have the impact the President and the disability community want and need.

I. Welfare to Work

1. Federal/State Efforts

In the last year, a growing number of states, with support from federal partners, have recognized the need to address disability issues in their local welfare populations to achieve the desired outcomes of welfare reform. For example,

- Washington State finalized and released a validated screening tool for identifying people with learning disabilities in the welfare population.
- Arkansas became the first state to implement the use of the Washington State screen statewide.
- Kansas has implemented a statewide program to integrate adult literacy and welfare reform efforts for people with disabilities.
- Six of the welfare to work discretionary grants awarded by the Department of Labor (approximately $20 million in funding) went to local applicants who will use the money to address the needs of people with disabilities in their local welfare populations.
- In 1998, the National Institute for Literacy and the Office of Vocational and Adult Education at DOE funded four regional training and resource centers on learning disability issues for adults and required these centers to prioritize welfare reform issues for their target populations.

2. Increased Federal Funding

As part of the final budget approved at the end of the 105th Congress, a number of measures designed to expand welfare-to-work activities received funding. For example, the final budget included $283 million for 50,000 new vouchers exclusively for people who need housing assistance to make the transition from welfare to work. In addition, the budget included $75 million to assist states and localities in developing flexible transportation alternatives, such as van services, to help former welfare recipients and other low-income workers to get to work. It also included an extended welfare-to-work tax credit for employers as an incentive for them to hire, invest in training, and retain long-term welfare recipients. Similarly, the budget extended the work opportunity tax credit, which encourages employers to hire disadvantaged youth, welfare recipients, and qualified veterans. *NCD commends the President and Congress for recognizing the need to address housing, transportation, and other barriers to enable people on welfare to obtain and retain employment. NCD encourages the President and administering agencies for these new programs to recognize that a large percentage of the population remaining on TANF has disabilities ranging from learning disabilities to psychiatric disabilities to substance abuse issues. Accordingly, many of these individuals must have their disability-related needs addressed in order for the goal of obtaining long-term employment to be realized. Moreover, NCD encourages the President and Congress to recognize that the current efforts to move people from welfare to work may have important lessons for the growing effort to move people from reliance on disability benefit programs to employment. Issues like housing, transportation, and health care must be addressed for the SSI and SSDI populations as well if the transition to work is to be successful.*

J. Housing

For people with disabilities to achieve optimal employment outcomes, they must be able to find accessible, affordable housing with links to accessible, affordable transportation that will take them to their job. A number of significant actions took place in the last year that advanced housing policy for people with disabilities.

1. Definition of Housing for People with Disabilities

HUD informed large cities and states that receive Community Development Block Grant (CDBG) and Housing Opportunities Made Equal (HOME) funds that people living in nursing homes and other service-centered facilities should be counted as being in need of permanent housing as opposed to being "housed." This statement was important because it recognizes the fact that institutional living does not constitute real housing for people with disabilities. It also will result in HUD receiving a more accurate and realistic count of the number of people with disabilities truly in need of housing. It is worth noting that even without this change in assessing the housing needs of people living in institutions, people with disabilities have been determined by HUD to be a population with the most urgent housing needs.

NCD commends HUD for taking steps to track more accurately the housing needs of people with disabilities. At the same time, NCD encourages HUD to act on its existing data and realign housing resources to respond more adequately to the appalling shortage in affordable, accessible housing in the community for people with disabilities. Moreover, NCD recommends that HUD further clarify its position on what constitutes housing for people with disabilities by issuing a policy statement to all recipients of HUD funds and placing the statement in fair housing materials and on its Web page.

2. Home Purchase and Renovations

On April 28, 1998, Fannie Mae announced the publication of *A Home of Your Own Guide*, the first manual specifically created to provide step-by-step homebuying guidance for people with disabilities. In early 1998, HUD included a disability rights organization (the Disability Rights Action Coalition for Housing) in a working group of major stakeholders in home ownership policy to implement a workable and effective homeownership program that will meet the needs of all people in the United States. Also, in early 1998, Secretary Andrew Cuomo issued a directive encouraging communities to use CDBG funds for home modifications for people with disabilities. *NCD commends Fannie Mae and HUD for taking these steps toward promoting homeownership and home modifications for people with disabilities. NCD encourages HUD to build on these steps by creating a national home modification fund for low-*

income people with disabilities, both renters and owners. HUD thereby will empower more people with disabilities to become homeowners or tenants in community settings.

3. Visitability

In HUD's recent Notices of Funding Availability, the agency included bonus points for developers when they seek to build or rehabilitate structures with three or less units that include visitability by people with disabilities. This visitability concept would require all such new housing to have at least one no-step entrance and 32-inch doorways so people with disabilities could visit their friends who live there. In addition, at the same time, Secretary Cuomo issued a notice to all jurisdictions encouraging them to adopt visitability standards for all new construction projects, including town houses and single-family homes.

Last spring, the HOPE VI program (a HUD-financed effort to replace housing resources destroyed when public housing projects are demolished) issued a Notice of Funding Availability strongly encouraging applicants to incorporate both visitability and section 504 standards in new projects that would not be covered by the Fair Housing Act. All applications submitted in accordance with this NOFA included visitability and section 504 accessibility standards. *NCD commends HUD for embracing visitability as a goal for HUD-financed housing and for recognizing that the move from project-based housing to town homes and other detached dwellings does not need to mean a reduction in accessibility if developers are encouraged to build in such features in the design stage.*

4. Tenant-Based Rental Assistance

Congress included $40 million in section 8 funding for people with disabilities, in part to offset the displacement likely to occur as a result of elderly-only designation of public housing formerly occupied by people with disabilities. *NCD applauds Congress for recognizing the need for substitute funding to enable low-income people with disabilities to find housing in the community, but believes HUD and Congress must go much further to expand funding for tenant-based rental certificates. In the past, HUD has used 25 percent of its section 811 program funds (Supportive Housing for People with Disabilities) for tenant-based rental certificates. NCD*

recommends that 100 percent of the section 811 program funds be used for person-based, rather than project-based, housing resources. This change would be consistent with the requirements in section 504 of the Rehabilitation Act and the Fair Housing Act that housing resources be provided in the most integrated setting appropriate.

5. Task Force on Segregation and Services Linked to Housing

One of the core debates within housing policy for people with disabilities centers on whether there are some circumstances under which people with disabilities may be required to live exclusively with other people with disabilities and/or to accept services in order to qualify for publicly funded housing. The resolution of this debate has important civil rights implications for people with disabilities, many of whom wish to live in integrated settings and to be able to seek services separate from their choice of where to live. For example, the Fair Housing Act and section 504 prohibit special terms and conditions and/or segregation based on disability status. Internally, HUD this Fall created a Task Force on Segregation and Services Linked to Housing, which will examine ways to maximize integration and individual choice in housing for people with disabilities. *NCD is concerned that the issues of segregation and services linked to housing are well-decided under section 504 of the Rehabilitation Act and the Fair Housing Act. Accordingly, NCD does not understand the purpose of this new task force, unless it will focus exclusively on implementing well-established civil rights policies.*

6. Compliance with Section 504 of the Rehabilitation Act by HUD and its Grantees

Under section 504 of the Rehabilitation Act, public housing authorities must ensure that 5 percent of any building with five or more units is accessible to people with mobility impairments, and 2 percent of any such building is accessible for people with visual or hearing impairments. Recently, as more and more public housing authorities have reoriented their emphasis away from housing projects and toward low-density housing such as inaccessible town houses, the number of units accessible for people with disabilities has been significantly reduced.

NCD recommends that HUD conduct an evaluation of its grant recipients and subrecipients under section 504 of the Rehabilitation Act to ensure that all of their programs and

services are in compliance. In conducting this evaluation, HUD is encouraged to move beyond a percentage mentality and promote the development and rehabilitation of housing that will meet the needs of all people.

Finally, NCD recommends that HUD reform the programs under which people with disabilities receive assistance with housing such as the section 811 program to ensure that these programs reflect the most integrated setting requirement of section 504 and independent living philosophy of the disability rights movement.

K. Transportation

Like housing, accessible and affordable transportation plays a vital role in enabling individuals with disabilities and their families to participate in the mainstream economic, social, and cultural lives of their communities.

1. Over-the-Road Bus Regulations

This past year witnessed a significant step forward in transportation policy when DOT issued the final regulation implementing ADA provisions for over-the-road bus (OTRB) accessibility in September 1998. The regulation, widely regarded as a strong rule by the disability community, requires large fixed-route operators to achieve 50 percent of full fleet accessibility by October 2006 and 100 percent by October 2012. An important strength of the regulation is that it provides a regulatory definition of discriminatory action: refusing transportation, using or requesting the use of non-employees in giving routine assistance without the passenger's consent, and asking passengers to reschedule their trips to a time other than their requested travel time. Properly implemented, the regulation will make OTRB transportation accessible for people with mobility impairments for the first time since ADA was enacted. As written, however, the regulation both supports and detracts from ADA's overall goal for "fully accessible, nondiscriminatory, everyday service."

Small fixed-route carriers and those providing demand-responsive or mixed service have no minimum percentage of fleet accessibility to achieve. Instead, these carriers will be required

only to provide an accessible bus on 48 hours' advance notice starting October 2001 (large carriers) or October 2002 (small carriers). New buses acquired by large fixed-route carriers after October 2000 must be accessible, while small carriers have no parallel requirement. Of 3,500 OTRB service providers, all but 21 are classified as small carriers. However, the major carriers serve the largest number of passengers.

Exempting most carriers from any minimum fleet accessibility requirement virtually guarantees that service to persons with disabilities will never be available on the same basis as to nondisabled passengers in many areas of the country. This outcome is not in keeping with the purposes of ADA. *Rather than accept less than full accessibility as the goal, NCD encourages DOT to find alternative paths for small operators to achieve full fleet accessibility over a longer time frame.*

DOT has strengthened the regulation by including provisions making OTRB operators individually and collectively accountable for providing accessible service. Each operator involved in providing service to passengers with disabilities on trips involving multiple transfers is responsible for communicating to ensure accessible service on all trip segments. Failures to provide the requested accessible service must be compensated at a rate ranging from $300 to $700. *NCD commends DOT for including provisions that clearly demonstrate its commitment to successful implementation of the regulation.*

NCD notes that a provision for DOT to conduct a regulatory review of all service requirements starting in October 2006 has positive and negative implications. On the positive side, DOT has set out the requirements it intends to reevaluate and what data it proposes to use. On the negative side is the possibility that the measurement data will not be maintained regularly and accurately. Without reliable data, DOT cannot make a fair assessment of the regulation's impact on the industry or the extent to which it has made OTRB transportation truly more accessible for people with disabilities. *NCD urges DOT to explore options and implement systems for ensuring the reliability of the data on which its analyses will depend.*

2. Air Carrier Access Act

The Air Carrier Access Act (ACAA), which became law in 1986, prohibits discrimination against passengers with disabilities by air carriers in providing air transportation services. The implementing regulation was passed in 1990. This year NCD conducted a study on DOT's enforcement of ACAA. The findings showed that DOT's enforcement model relies heavily on monitoring of complaints and voluntary compliance by air carriers. This approach does not emphasize traditional investigation and prosecution of complaints similar to other federal civil rights enforcement agencies.

Accordingly, NCD believes that DOT's approach is critically lacking in the key areas of compliance monitoring, complaint handling, and leadership. No regular program of ACAA monitoring ensures compliance in day-to-day airline operations. DOT's informal complaint-handling process serves more as a tool for monitoring the industry than as a system for resolving individual discrimination claims. Even the formal complaint process focuses only on issues of broad public interest, so that individual complainants have no reliable administrative means to obtain satisfaction unless the airline voluntarily cooperates. NCD's research shows that DOT's leadership in addressing difficult compliance problems (e.g., providing lifts and other boarding devices, regular training of airline personnel, and ensuring that new aircraft meet accessibility standards) has been inadequate.

The problems of ACAA enforcement arise from inadequacies in DOT's enforcement mechanism and in the law itself. Unlike other civil rights laws, ACAA does not explicitly establish a private right of action and contains no provisions for attorneys' fees and damages. The law also fails to extend the nondiscrimination mandate to foreign air carriers operating in the United States as code-sharing partners of domestic airlines. *NCD urges DOT to seek additional resources for enforcement of ACAA and to target specific areas where it will initiate action—in concert with the disability community, the aviation industry, and other stakeholder groups—to correct persistent implementation and compliance problems. NCD also encourages Congress to increase DOT's ACAA enforcement budget and to amend ACAA extending its nondiscrimination*

mandate to all airlines serving U.S. markets, strengthening DOT's enforcement mandate, and authorizing those whose civil rights have been violated to obtain appropriate legal remedies.

L. Technology

Over the past year, several significant events have advanced the potential for individuals with disabilities to use the Internet and have access to the equipment they need to work, gain an education, and live independently. Of greatest significance are the changes to section 508 in the Rehabilitation Act Amendments of 1998, which strengthened the obligations of federal agencies to provide accessible technology and information to their employees, customers, and stakeholders.

1. Section 508 of the Rehabilitation Act

When section 508 was originally enacted in 1986, it required federal agencies to purchase office equipment that was accessible to its employees. However, no mechanism enforced this requirement. Furthermore, only technology manufacturers, and not individuals themselves, could file complaints. Now section 508 has been modified to grant authority to the Access Board for issuing accessibility regulations, which must be completed by February 7, 2000 (18 months after the amendments became law), and federal agencies must comply six months after that. Additionally, federal employees, as well as members of the public receiving services from the agency, now have the right to file a complaint under a procedure similar to that outlined under section 504 of the Rehabilitation Act.

Strong compliance with these regulations will have significant implications for people with disabilities who work for or receive services from the Federal Government and for the disability community at large. The Federal Government can use its considerable purchasing power to influence private industry toward developing universally designed technology that is

accessible to everyone. One example of the impact of the Federal Government on technology development was the refusal of DOE to purchase Lotus Notes software until access modifications were made. Pursuant to DOE's software procurement policy, which was developed in consultation with experts in accessible software standards, DOE will not purchase any software product for use by its employees that does not meet minimal accessibility standards. For example, to meet such standards, software must be completely operable with keyboard commands rather than requiring mouse navigation; must allow for compatibility with screen reader and voice input programs; and must have accessible product support, including accessible documentation, training materials, and technical support. DOE's insistence on access has led to the development of more accessible Lotus products. *NCD encourages other agencies to take their example from DOE and adopt its accessible software procurement standards during the period while the section 508 accessibility standards are being developed.*

2. Section 255 of the Telecommunications Act

Another significant technology development this year was the issuance of proposed regulations to implement Section 255 of the Telecommunications Act of 1996. This law requires that telecommunications equipment and services be accessible to individuals with disabilities, where readily achievable. In June, the Federal Communications Commission (FCC) proposed rules to implement this section of the Act. *While NCD was pleased that FCC proposed these overdue regulations, and that Chairman William Kennard has publicly expressed support for the development of accessible technology, NCD is disappointed that FCC is considering such a narrow definition of "telecommunications." It is astounding that voice mail, faxes, e-mail, and other commonly used electronic communications tools may not be covered. Such a narrow definition seems at odds with the intent of Congress and a commonsense understanding of telecommunications in the 1990s and beyond. The failure to regulate even the most commonly used forms of telecommunications will result in the exclusion of people with sensory and other impairments from basic communications devices and services, to say nothing of those yet to emerge from the rapidly changing Information Age.*

3. ADA and Section 504 of the Rehabilitation Act

Prior to the period covered in this report, Congress enacted other laws to ensure information access to individuals with disabilities, including Titles II and III of ADA and section 504 of the Rehabilitation Act. Unfortunately, federal agencies with enforcement authority for these laws have lagged behind in their compliance monitoring. In particular, the DOJ has failed to issue any advisory guidance on access to information kiosks operated by units of state and local government and has not issued significant guidance or consent decrees related to technology access. Only in September 1998 did DOJ assign a specific individual from its Disability Rights Section the responsibility to develop expertise in technology issues. *NCD urges DOJ to prioritize technology access issues in its implementation of ADA.*

4. Assistive Technology Act

For the past ten years, DOE has funded projects at the state level to promote systems change and advocacy activities that enhance access of children and adults with disabilities to assistive technology devices and services. These projects were authorized under the Technology-Related Assistance for Individuals with Disabilities Act. In October 1998, Congress passed a law called the Assistive Technology Act. This law continues block grants to states for public education and advocacy related to assistive technology products and services. In addition, the law authorizes a new micro loan program to encourage the development and purchase of accessible technology-related products and services. *NCD is disappointed that more emphasis was not given to promoting universal design or built-in accessibility, as contrasted with assistive technology or add-on accessibility. The rapid rate of technological change makes it increasingly difficult for compatible assistive technology to be developed before new versions of related mainstream products are released on the market. In addition, NCD recommends that more be done to promote training on use of the Internet, such as through public libraries, because of its revolutionary potential to empower people with various disabilities in education, employment, and civic activities. Independent, consumer-driven evaluations of technology also should have been specifically encouraged, since consumers face a bewildering array of options and have*

difficulty making informed decisions based mainly on product marketing literature. Finally, since people with disabilities and their families are disproportionately poor, it is critical that technology resources be affordable or available in free, accessible public venues if the disability community is to keep pace with the Information Age.

M. International Issues

As ADA continues to serve as a model of civil rights legislation for countries throughout the world, there is strong international interest in how ADA implementation is proceeding. NCD remains confident that the results of our ADA monitoring project will continue to attract interest. In the interim, the last year witnessed significant developments in the international arena.

1. Organization of American States

The Organization of American States (OAS) continues to consider the "Inter-American Convention on the Elimination of All Forms of Discrimination by Reason of Disability." This convention, when passed, will create an opportunity for OAS to carry out a great responsibility to ensure that all its state members observe the convention. *NCD encourages the U.S. Permanent Mission to the Organization of American States to work to see that the Convention is adopted with strong antidiscrimination provisions and to advocate that the Convention be fully implemented by each State Member when it is passed. In addition, NCD again commends the Department of State, including the U.S. Organization of American States, for its efforts to involve NCD and other disability community stakeholders in reviewing draft policies.*

2. Department of State

NCD encourages the Department of State to take steps to ensure that all aspects of U.S. foreign policy and assistance recognize the human rights and civil rights of all people with

disabilities, by ensuring compliance with the Architectural Barriers Act, Section 504 of the Rehabilitation Act, and ADA in U.S. embassies, consular offices, missions, and other U.S.-owned or leased property abroad; including relevant information about the status of people with disabilities abroad in U.S. government-generated country reports; promoting democracy through the sharing of U.S. laws and policies that promote inclusion, independence and empowerment; and conducting self-evaluations under the Rehabilitation Act for all U.S. government agencies active abroad to identify barriers to participation by qualified people with disabilities and to establish transition plans to eliminate these barriers.

Similarly, NCD encourages the Department of State and the United States Agency for International Development to ensure that all foreign aid and assistance is developed and delivered in a manner that ensures full participation and accessibility by all people with disabilities and their families in the geographic region served by the aid or assistance. If this practice were followed, the United States would not have recently permitted Bosnia to use U.S. aid to purchase thousands of dollars worth of inaccessible buses.

Finally, NCD encourages the Department of State to take steps to ensure that people with disabilities are a significant part of the work force at all levels of domestic and international operations by U.S. agencies handling international activities.

CONCLUSION

Increasing the employment rate of people with disabilities and expanding choices in home- and community-based long-term services and supports are two of the most significant issues in disability policy today. Neither of these issues is subject to quick and cheap solutions. Both require bold steps by the President and Congress, and both require multifaceted solutions. On the employment front, it is critical to recognize that early intervention and lifelong development of human capital must be part of the solution. For children with disabilities, employment goals should be established early in their educations, and the development of marketable skills must be emphasized in the classroom and in work-study placements. People who acquire disabilities as adults must receive the comprehensive medical and vocation rehabilitation they need in a timely manner, coupled with access to accessible and affordable transportation and housing and a technological infrastructure that will ease the transition back to employment.

On the issue of long-term services and supports, including consumer-directed personal assistance services and family supports such as respite care, the President and Congress must recognize that children and adults with significant disabilities and their families can contribute more to the economy and enjoy a basic standard of living taken for granted by many in the rest of the population if we eliminate the institutional bias in Medicaid and require states to honor the human rights of their citizens with disabilities to live where they choose with adequate supports to participate fully in community life. Finally, for both the employment issue and the long-term services and supports issue to be addressed effectively, the President and Congress must work together to remove the work disincentives from our Social Security, Medicaid, and Medicare systems. Americans with disabilities are poised to take their place in the mainstream of their communities, but they are too often thwarted in this desire by outdated federal policies and programs. Now is the time for the President and Congress to carry out President Bush's promise

that people with disabilities be given "the opportunity to blend fully and equally into the right mosaic of the American mainstream."

APPENDIX

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

Overview and Purpose

NCD is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to

personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the secretary of education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies on ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration regarding the policies and conduct of the Rehabilitation Services Administration.
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the

purposes of NCD to promote the full integration, independence, and productivity of individuals with disabilities;

- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

International

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities,

monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

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